



a survivor's story

From the Australian Cancer Survivorship Centre



Natalia Dewiyani's story, as told by Meg Rynderman, a consumer representative for the Australian Cancer Survivorship Centre

Interviewed: May 2018

'One smile a day'

Natalia Dewiyani

You may have noticed her standing blindfolded in Federation Square offering free hugs, on the television news described as "Peter MacCallum's huggiest patient", or come across her website, which outlines her goal of collecting one million hugs in her lifetime.

I recently met with diminutive 40-year-old Nat Dewiyani at Peter Mac. She greeted me with a broad smile, laughter and an enfolding hug, and then she told me the story of her cancer journey.

The only daughter of the family, middle child Nat was born to Chinese parents in Yogyakarta, on the island of Java in Indonesia. She came to Melbourne in 1996, at the age of 19, to study IT at Melbourne University. Her oldest brother followed four years later.

Raised in a culture where displays of affection were not the norm, Nat talks of enjoying the "huggable culture" of Australia. She explains that the inspiration for Hugs for Change grew from a desire to raise money for charities when a friend joked that "if I charged a dollar [for each hug], I'd be a millionaire".

Life took on its own rhythm – study, friends, relationships, graduation and a web design business. Then, in 2007, Nat

went through a difficult time, which she refers to as "her life challenges". She experienced a period of depression.

"I was really feeling so alone and hopeless. It feels like there is nothing you can do and you're hitting a brick wall."

What followed she describes as a spiritual experience.

"I was at the lowest of my low. In my despair, somehow I ended up praying and in that moment I felt a blanket of love wrapped around me. Even with all my flaws I was still loved and that's what healed me. I believe that is why I have so much love to give because I have experienced what it feels like to be loved unconditionally. From then on, I made a promise to help others."

In 2015, Nat was treated for what was suspected to be a labial cyst, which continued to grow despite a course of antibiotics. Her GP sent her to emergency at the Royal Women's Hospital.

"At least nine different doctors looked at me and they just said, 'Oh, this is interesting, let me call my colleague,' and I had all these doctors coming in and they had no idea what it was. But they ended up making a decision to remove the mass."

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A post-surgery follow-up visit revealed unexpected pathology results and a diagnosis of Ewing sarcoma. Mostly seen in children and young Caucasian males, Nat's diagnosis was also rare due to the location of the mass.

Arrangements were made for her to see a specialist at Peter Mac. She talks of her shock and confusion at the news, commenting particularly on the disruption that a cancer diagnosis causes to young people.

"They told me, 'You've been diagnosed with Ewing sarcoma and treatment requires about 40 weeks. It's 14 cycles of chemo and radiation and will take about 10 months'. And so I said, 'What do I do with my life?' That's a long time and you obviously just don't know what to do. No-one ever prepares you for this – what to do when you have cancer treatment.

"I think there's a lot of information you need, especially someone who's young and didn't expect to have cancer. It's definitely a whirlwind and that's why I understand when

cancer patients come in and they're just like, 'I just don't know what to do,' 'What's going on?' – you know now your death is so close to you."

Young patients up to the age of 25 come under the umbrella of AYA [adolescent and young adult] wards and support. Nat, too old to be considered a young adult, reflects on her age and the impact it had on her treatment.

"I would be the one who was out in the middle. The patients would be either too young or too old. It [was] very rare for me to meet someone my age."

She reflects that neither her partner nor her friends had any experience dealing with major life matters like cancer.

"This is not a conversation for someone my age and I think her [my partner's] struggle is that there is no-one in our friends' circle who she can talk to, who can understand. They're scared, so scared – they want to know what's happened and then

they think of how you would want a funeral to be and all these things that people don't talk about."

She is grateful for the support of her family, her friends and the fact that she is not alone.

"I just feel I'm quite lucky in a sense, because I have the support network that helped me through. Three days before I started my first treatment, we started a fundraiser; all of my friends, they got together and raised funds for me, to help me along the way, and I had 10 other friends who shaved their head with me.

"I was lucky to have started my treatment with such positive energy, not just from me but my friends as well who were there with me. I'm blessed in a way that I have the support network; I know that some people don't – it's a tough thing to get through by yourself."

Despite the support, Nat comments on the awkwardness and discomfort that some of her circle felt around her and her cancer diagnosis and treatment.

"Sometimes – and that happened to a lot of my cancer friends [too] – some people in their lives stop talking to them after their diagnosis and you wonder like, 'What's happening?' I would love to start more conversations around this."

For people who have friends who receive a diagnosis of cancer, Nat advises, "Don't not talk to them, because they need you. If you don't know what to say, just tell them, 'I might say the wrong thing but I just want to be here for you'."

She reflects on the time her father passed away quickly and unexpectedly a few years earlier, which prompted in Nat a desire for a career change.

"It really makes you question in terms of what do you want to do with your life and what matters in life. That's one of the reasons I changed career from



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IT to life coaching. I am grateful to have gone through what I had gone through before my cancer diagnosis as it allows me to have emotional toolkits to face cancer with a smile.

"I'm passionate about inspiring people to have their emotional toolkits, to be more open and be more connected. I want to inspire people to create that deeper connection with each other. That's why I always bring laughter and hugs because they are the things that help people to connect."

Treatment for Nat was difficult, protracted and very painful, including several visits to the intensive care unit (ICU), but she took with her the knowledge she had learned.

"That's why I said I'm going to smile every day, no matter what, because I don't ever want to go back into that dark place that I know is going to take me into despair. So now I

don't focus on my darkness; I focus on the light and other people's light and bringing light to others.

"I'm not saying that it was easy; I had many days when I cried, many days when I just felt so weak and vulnerable, especially when you're in ICU and you feel so sick and time just seems to go so slowly. And there are times when you feel so fragile, but even then I know I still have a choice to make cancer my blessing [rather] than my curse."

She started a Facebook page, Laughter with Cancer, and she did smile every day and has every day since. She took photos and made videos of her journey and still posts daily onto her page – photos of her with her nurses, with her doctors and other patients, laughing and joking and dealing with her painful experience in a way that brought joy to everyone who came into contact with her.

Severe reaction to chemotherapy and radiation led to an abrupt cessation of treatment, followed by a year of pain and discomfort. Nat continues to take one day at a time.

"I remember when I finished treatment, I couldn't see my life past treatment and even during treatment you couldn't see your life past the next day. You know you have to really bring yourself back into the present, because that's all the energy you have."

Nat speaks of the variety of stresses that a cancer diagnosis can cause.

"I find most cancer patients are such givers; they struggle to ask for help. You have to have the courage to ask for help."

Nat reached out to the Cancer Council 13 11 20 support line.

"I got connected to the Cancer Council, I called them just to figure out my finances and what I can do and then during the treatment my partner was having a really tough time and sometimes even my partner had to seek help from someone else."

She explains that finishing treatment and the uncertainty of what happens after that can bring its own particular stresses.

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"What happens after treatment? And this is from all of us – all of my friends [fellow patients] across the board – treatment has stopped: what do you do now? And we just felt so lost, just as lost as when you first get your diagnosis to the moment that [someone says], 'This is it: you're done'. What do you do?"

A year after her first diagnosis, Nat came through a melanoma scare, fortunately caught and removed early. She jokes that she "wasn't sure how to react" when told she should be proud that she had "nailed and defeated two cancers under the age of 40".

Nat names the fear common to many patients, of their cancer coming back, commenting that "the unexpected diagnosis of melanoma does not make the process easier". Over time, as the hospital visits become less frequent, the thoughts become less loud. She acknowledges that while she is managing her "scanxiety", as she calls it, the waiting room is a challenging place to be.

"When I went back to the waiting room this week before my scan I was there by myself; usually I have someone with me. But, I'm strong enough now; mentally I'm OK to do that. And then I saw the people and all the memories started coming back."

Rather than thinking of herself as a survivor, Nat prefers to label herself a "thrivor". She sees her GP as an integral element of her healthcare team and comments on the importance of wellbeing as part of treatment.

"[My] GP, she's been great in terms of paying attention about my health and wellbeing. This is health care – this is where we are supposed to have our wellbeing, not just physical but also the mental side of it.

"My 'accidental' promise to smile daily has allowed me to focus on the positive, which gives me hope and strength to get me through my treatment. I want to pass on this simple but powerful ritual to my cancer circle. Our mental health is just as important as our physical healing during treatment."

Nat finishes her time with me with a hug and a smile, photographing us for her daily website upload, repeating her mantra:

"How can I empower others to know that they also can do what I do, which is one smile a day? If you can smile, then even a bad day can turn into a good day."

Further information and support:

- **The Australian Cancer Survivorship Centre – A Richard Pratt Legacy (ACSC)**

The ACSC is a web-based centre.

www.petermac.org/cancersurvivorship

- **ACSC factsheets**

- Emotional impact of cancer and its treatment fact sheet
- Fear: Coping with the fear of your cancer coming back fact sheet
- How your general practice can support you to live well

<https://www.petermac.org/services/support-services/australian-cancer-survivorship-centre/survivors-and-carers/resources>

- **Cancer Council**

Contact the Cancer Council Support Line on 13 11 20 for information about side effects from treatment, or any other questions you have about cancer and surviving cancer.

www.cancer.org.au

- **Cancer Council - coping with a cancer diagnosis fact sheet**

<https://www.cancer.org.au/content/pdf/Factsheets/After-a-diagnosis-Coping-with-a-cancer-diagnosis-2013.pdf>

- **Cancer Australia sarcoma information**

<https://sarcoma.canceraustralia.gov.au/>

- **Beyond Blue - recovering from a mental health condition**

<https://www.beyondblue.org.au/get-support/staying-well/recovering-from-a-mental-health-condition>

- **Laughter with Cancer**

<http://laughterwithcancer.com/>

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